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# Consent for Data on Consent

Mollie Gerver

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## Abstract

There are instances where the provider of an intervention, such as surgery, has failed to obtain necessary informed consent from the recipient of the intervention. Perhaps a surgeon has failed to warn the patient that she may go into a coma, or even be killed, from the surgery. Sometimes, as a result of this intervention, the recipient cannot give informed consent to researchers for the release of their personal data precisely because of the intervention. If they are in a coma, they cannot be reached. Sometimes, this personal data itself can prove that the provider of the intervention failed to obtain informed consent for the intervention. For example, a personal file may include a consent form that does not include warnings about the risk of falling into a coma from the surgery. Paradoxically, those who cannot give informed consent for the disclosure of their personal data on an intervention may have been especially ill-informed about the repercussions of the intervention. In such instances, should researchers ever use the data and disclose the data in their research? In an attempt to demonstrate when this dilemma may be relevant, and how it may be solved, I will present a real-world case of this dilemma in my own empirical research on refugees who agreed to repatriate to their countries of origin from

Israel. I will consider what theories on consent, if any, can help us resolve this dilemma

## 1 Introduction

There are times when refugees want to return to the countries they fled from, despite the risks. When making such a choice, they may ask governmental and non-governmental organizations(NGOs) for help with flights, travel documents, and other assistance. Such services are provided by immigration authorities, private companies, charities, and the United Nations, which has repatriated millions of refugees over the last decade (UNHCR 2012). These “repatriation facilitators” have a responsibility to ensure informed consent in return. They therefore give refugees a set of questions to answer to ensure they are informed and not repatriating as a result of coercion or duress, such as fear of being detained or deported. Below are some of the questions asked by one NGO in Israel which helped refugees return to Sudan and South Sudan between 2009 and 2012:

“Do you know people who have returned to Sudan from elsewhere?

If yes, what is their situation there?

What, if anything, would make you change your mind about...[going]

back to Sudan?<sup>1</sup>

Each question was aimed at determining if a refugee was informed about their decision, and not compelled by the Israeli government to leave. Each answer would be recorded, transcribed, and filed away in a secure file cabinet.

During my research, I asked the director of HIAS if I could look at the answers refugees gave. The answers, I told him, could help determine if refugees were fully informed about the risks of returning, and if they were returning from detention. In other words, I would be able to determine if refugees had given HIAS their informed consent to return to South Sudan and Sudan. The director acknowledged the importance of the research, but informed me that, to look at the answers, I needed to first call those who returned and ask them for their permission. If they consented to me looking at their files, HIAS would give me copies of them.

Unfortunately, I could not contact all of those who returned. Many were killed, and others displaced, possibly contrary to what HIAS had promised. Others were living in extremely rural areas, unable to access telecommunications or safe and reliable roads, also living in conditions that were possibly different to what they expected prior to repatriating. Paradoxically, the reason many could not give their informed consent to disclose their data, meant to determine if they gave informed consent to repatriate, was precisely because they repatriated to a country without giving their informed consent.

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<sup>1</sup>HIAS Interview Form, Provided by HIAS in December 2012.

This article attempts to establish when researchers should look at data on refugees after they have repatriated, and cannot be reached. The issues raised are applicable to other cases where researchers cannot ask individuals for their consent to releasing their data, when the data is related to an earlier intervention which itself had questionable informed consent. Importantly, I focus on scenarios where the reason they cannot give their informed consent to disclose their data is precisely because of the intervention.

This last aspect – that the intervention caused them to be unable to consent to data disclosure – is important. To see why, consider the following fictional case. A doctor gives medication to a patient, never warning him that he may fall into a coma. He takes the drug, and quickly loses consciousness. Researchers ask the doctor if they can look at the consent form the patient signed, and his medical history. “I am sorry,” the doctor responds, “but I cannot show you his data unless he consents, and he cannot consent because he is in a coma.” When following this rule of thumb, the doctor has less of an incentive to warn patients of dangerous side effects, knowing she is unlikely to be held accountable for her failure to ensure informed consent in the intervention. The doctor also has an interest in the patient staying a coma, further ensuring she will not be held accountable. Perhaps the data should not be disclosed. But if we can find an ethical justification to look at it, this can ensure more ethical interventions.

In the following section, I will demonstrate that we cannot determine the right course of action by appealing to classic theories of consent, which ask what a subject’s own preferences are. For, we often do not know enough

about their subjective preferences, because we cannot contact them. In Section 3 I argue that we should instead consider whether they have “object-given reasons”<sup>2</sup> to disclose their data. These are reasons a person has to consent to an act, regardless of their subjective preferences. In Section 4 I suggest we weigh these certain object-given reasons to disclose data against possible subjective reasons not to disclose their data.

The article will draw upon examples from my own research on repatriation of refugees in Israel back to South Sudan and Sudan between 2005 and 2012, a significant number of refugees crossed the border from Egypt into Israel, after failing to secure refugee protection in Egypt. By 2009 there were 22,000 refugees in Israel, including 4,300 from Northern Sudan and 1,250 from present-day South Sudan. They were given informal group protection by the Israeli government and not deported, but also not recognized as refugees. Some had medical care and education, but many did not. Some were arrested, but others lived in relative freedom.<sup>3</sup>

One private NGO, Operation Blessing International (OBI), began facilitating repatriation for them in 2009. In South Sudan, access to medical care and other services was extremely weak that year, and still is.<sup>4</sup> It is also illegal in Sudan to set foot in Israel, punishable by death. Concerned, OBI and another NGO, the Hebrew Immigrant Aid Society (HIAS), asked refugees if

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<sup>2</sup>Parfit 2011 *ibid*

<sup>3</sup>Y Berman, "Until our hearts are completely hardened: Asylum procedures in Israel," Hotline for Migrant Workers, 2011

<sup>4</sup>D Maxwell, K Gelsdorf, M Santschi, "Livelihoods, Basic Services, and Social Protection in South Sudan," Working Paper 1, 2012. Secure Livelihoods Research Consortium. Feinstein International Centre

they were coerced into leaving and knew about risks. Both NGOs told me they refused to facilitate misinformed or coerced returns. To validate these claims, between 2012 and 2014 I travelled to South Sudan for four months and to Uganda and Ethiopia for two months, as many had fled or migrated to these countries after return. The majority of the 121 individuals I interviewed, in urban and rural areas, told me they thought there would be employment, free healthcare, and free education in South Sudan. In the end there usually was not. Many said they returned solely to avoid detention in Israel or because their work visas were revoked

Amongst the individuals I interviewed, those I found it most difficult to contact were without cell phones, in refugee camps, and in rural areas far from roads and safety. These individuals were also the least informed about South Sudan before they returned, and the most harmed after they returned. This suggests that, if we were to only view the pre-return data of those I could call to ask for consent, there would be a bias towards those who did give informed consent to repatriation, as these individuals were easier to contact. Looking at all interview-based questionnaires would allow me to fully determine the extent that repatriation was with informed consent. Yet, this would be at the expense of returnees' right to privacy, and thus their right to first give their informed consent before others look at their private data.

## 2 Consent

To consider what ought to be done, we might consider three theories of consent, which focus on three distinct factors: autonomy, reasons, and time. The first theory considers what a person's autonomous preferences are. The second theory considers what a person could have reasons to want, if they are unable to say what their preferences are. The third theory considers when we ought to accept a person's earlier consent as valid at the present time. I will show that these theories, though helpful, are often unhelpful for determining what ought to be done.

### 2.1 Autonomy

A person's decision is autonomous if they are fully informed and not coerced into their decision.<sup>5</sup> Sometimes decisions are without coercion or misinformation, but based on non-autonomously developed preferences. For example, the "the hopeless destitute" may prefer their positions in life, but only because of their position (Arneson 1994; Sen 1987). Other times, though, a decision is made because of these conditions but to escape them, such as the "hopeless destitute" accepting a low-paying job that improves their conditions. It seems that such offers are autonomous unless the offer-giver is also the agent that is doing the coercing. A wealthy factory owner who steals from the poor to get the poor to accept lower salaries is coercing the

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<sup>5</sup>TL Beauchamp and JF Childress JF Principles of biomedical ethics, 6th edn. Oxford: Oxford University Press 2009



poor into their decisions, making them non-autonomous. Sometimes, the offer-giver is not coercing, but ought to help more.<sup>6</sup> Imagine public fireman who offers to put out the fire for a desperate victim, but charges millions of dollars. The victim's consent to this offer is possibly non-autonomous. This is not because the fireman did any coercing – it is not her fault there was a fire. Rather, it is because she ought to put the fire out for free or much less than millions of dollars, because of her professional duties, the urgency of the situation, or the fact she can for far less than millions of dollars.

There are two instances in repatriation that may involve non-autonomous interventions. The first is when an NGO helps a refugee repatriate without obtaining their autonomous consent. The second is if researchers look at their data without obtaining their autonomous consent.

One reason NGOs may fail to obtain autonomous consent when helping with repatriation is if a refugee is repatriating because of government coercion – such as detention. An NGO may be partly culpable of the refugee's non-autonomous choice to return if the NGO has a duty to lobby to stop government coercion but only helps with return. Similarly, if an NGO somehow causes coercion, then they act unethically by helping with a coerced return. This might be the case if an NGO, by helping refugees repatriate from detention, frees up a detention cell, allowing the government to detain a new refugee who otherwise would be free. A refugee's choice is also non-autonomous if NGOs give false information, or fail to disclose pertinent

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<sup>6</sup>Joseph Millum (2014) Consent under pressure: the puzzle of third party coercion. *Ethical Theory and Moral Practice* 17(1): 113–127

information. In summary, NGOs have failed to respect the autonomy of refugees in repatriation if they have

1. Coerced refugees into repatriating or
2. Failed to fulfill their duty to help stop coercion or
3. Failed to inform the refugee about the risks of return

The second instance where autonomy is undermined is if researchers look at the personal data of refugees who has returned against refugees' wishes. Autonomy is also undermined if a refugee wants to disclose their data, and cannot, because they cannot be contacted. In addition, those who were coerced to return may have been forced to keep their data private at the time of return. If they are in detention, they may accept a free flight home, and in accepting the flight, are required to sign a data-protection form, which states their data will not be disclosed without their express consent. In other words, they are coerced into keeping their data private, because this is a condition for their returning, and they are coerced into returning.

Similarly, if a refugee is ill-informed about the risks of return, a refugee will be ill-informed about the risks of keeping their data private. For, she will not know that, in keeping her data private, the NGO will not be held accountable for giving misinformation. In general, outside the sphere of refugee repatriation, misinformed interventions may entail misinformed consent to keeping data private. If a doctor does not tell a patient that medicine might put her in a coma, the doctor will also not tell a patient, "If you keep your

data private, nobody will ever be able to arrest or sue me for failing to tell you about the risks of a coma.” Whether the intervention itself had informed consent can provide evidence as to whether the choice to keep data private was with informed consent.

In order to determine whether data should be disclosed, we might conclude that different policies should be implemented in two different scenarios:

Consent Scenario 1: Researchers know from other evidence that an individual has not given valid consent for repatriation. For example, perhaps a refugee has already been interviewed by a researcher after return, and told the researcher that they were coerced into returning, providing further evidence of their coerced return.

Consent Scenario 2: Researchers do not know if an individual has or has not given valid consent for repatriation. The only data on refugee’s return is in their private file.

If refugees have not consented to repatriate, as in Scenario 1, this is strong evidence they have not truly consented to keeping data private. It would be less problematic to disclose their data. But even if we are fairly certain refugees have not autonomously consented to repatriation, this does not mean they now want their data disclosed. Some who returned do not want to publicize information they feel is very private, such as their sexual orientation. Individuals have a right to such privacy. Others may fear data being leaked to government authorities, risking their lives in the country

they now live in. While this may be rare,<sup>7</sup> the more who see the data, the greater the risks.<sup>8</sup> I was told of one such leak from a major international organization helping with return. These and other concerns may be in the minds of refugees when they consent to keeping their data private. As such, they were not necessarily coerced into their decision.

There is a more basic problem in disclosing data in Scenario 1. In such scenario, we already know there was no informed consent to repatriation, so there is no urgency in looking at the data. We already have evidence to hold repatriation facilitators accountable. While it is true that there is greater evidence that former refugees would consent to their data being disclosed, there is less of a reason for researchers to disclose the data, and so less of a justification for their doing so.

In Scenario 2 we have no idea if those who returned were misinformed or coerced into returning, and so there is a much stronger justification for looking at the data. But if we open up the file in Scenario 2, and find out they did consent to repatriate, then it seems the former refugees really did consent to their data being kept private. For, they were fully aware of the risks of return, and not coerced into returning, so were both aware of the risks of keeping data private and not coerced into doing so. Moreover, even if we open their file and see they did not consent to repatriate, we do not know this until after we open their files. Their privacy is breached when we

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<sup>7</sup>AP Schwab, Frank L, Gligorov N (2011) Saying privacy, meaning confidentiality. *American Journal of Bioethics* 11(11)(2011):44-45

<sup>8</sup>T Schonfeld, JS Brown, NJ Amoura, B Gordon, You don't know me, but...: Access to patient data and subject recruitment in human subject research. *American Journal of Bioethics* 11(11)(2011)31-38

open their file before we have a justification.

The route of the problem is that returnees cannot be reached. To consider what to do, we might consider what is done in medicine when an individual is in coma or mentally impaired, and so cannot give their informed consent. Bioethicists emphasize that, in such cases, third parties should never see this information.<sup>9</sup> The literature emphasizes the problem of over-sharing: vulnerable patients lack the capacity to understand the implications of disclosing their data. But there is little emphasis on the problem of under-sharing: vulnerable patients lacking the capacity to understand the implications of not disclosing their data, possibly protecting doctors who failed to obtain informed consent for an intervention.

In such cases, rather than never looking at the data, or always looking at the data, perhaps we can ask what a person would have reasons to consent to, if we could ask them. I will now consider this approach.

## 2.2 Reasons

Even when we cannot ask a person what they prefer, we can ask what they would hypothetically prefer. There are two ways to determine this. We could ask, “What would a reasonable person want?” This would involve appealing to what people generally want, such as safety, food, and shelter.

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<sup>9</sup>B Dolan, Medical records: disclosing confidential clinical information. *Psychiatric Bulletin* 28(2004):53–56; R Cushman, AM Froomkin, A Cava, P Abril, KW Goodman, Ethical, legal and social issues for personal health records and applications, *Journal of Biomedical Informatics* 43(5)(2010): S51-S55

This is the approach often taken in medicine, when a surrogate that must decide on behalf of a never-competent patient. For example, if a patient has lived with the capacity of a six year old since childhood, a surrogate may consider what is in her interests, rather than what she earlier stated she wanted.<sup>10</sup> We might similarly argue that, if a refugee has never stated their preferences, then researches should consider what a reasonable person would want. This approach, while useful in cases of never-competent patients, would be problematic in cases of refugee repatriation, as it ignores refugees' unique subjective reasonable preferences, which as competent people they do have, even if we cannot reach them. Rather than asking what a reasonable person would want, we can ask, "What would this particular person want, were we to call them up and ask them?" To answer this, we can consider what they personally would have reason to want.

As before, there are two sets of reasons to consider: reasons to repatriate, and reasons to disclose data.

It would seem that repatriation facilitators have committed an injustice if a refugee who returned would have had no reasons to return had they been given full information, and had facilitators provided assistance they had a duty to provide. For example, imagine that the UN fails to help refugees gain refugee status, refugees are detained, and the UN then helps with repatriation. It would seem the UN has committed an injustice if the refugees would have had no decisive reasons to return, had the UN fulfilled

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<sup>10</sup>N Cantor, The bane of surrogate decision-making: defining the best interests of never-competent persons. *Journal of Legal Medicine* 26(2)(2005):155–205

its duties to help refugees gain refugee status and be free from detention. Conversely, some people would have returned regardless, because they had other reasons to return, such as their patriotism or the fact that they missed their families. For such returnees, it seems a lesser injustice has occurred, because they would have returned even if they had not been coerced.

Let us now address the second set of reasons: whether a returnee now has decisive reasons to consent to disclosing their data. This is related to the first set of reasons concerning repatriation. If an individual would have had no reason to return if they had been informed and facilitators fulfilled their duties, then returnees would likely have strong reasons to disclose their data now. For, their decision to return was due to the failures of the repatriation facilitators, and they would want to hold the facilitators accountable. If, though, a refugee had good reasons to return even with full information and freedom in Israel, then perhaps the refugee would now have little reason to disclose their data. For, their decision to return was not impacted by the failures of the repatriation facilitators.

Consider, for example, the case of Simon, a refugee who was told false information by NGOs in Israel, but who says would have returned even if he was given accurate information, as he knew what to expect from personal sources. As such, he does not blame OBI for any wrongdoing. Nor does Joseph. He returned in 2011 with tens of thousands of dollars in savings and opened a successful Playstation arcade in Juba. He assured me he would have returned regardless of how OBI and HIAS acted. Consider also the case of Yasmin. She says she was misinformed by OBI about medical care and

security in South Sudan, but would have returned even if more information was provided to her, because she missed her family, and wanted to start a restaurant in Aweil. All three – Yasmin, Simon, and Joseph – would have little reason to disclose their data. For, they would not feel it necessary to hold the NGOs accountable, as they did not feel they were coerced into returning.

If having reasons to repatriate impacts whether one has reason to disclose data, then researchers should perhaps act differently in three scenarios.

Hypothetical Consent Scenario 1: Researchers know from other evidence that an individual would have had no reason to repatriate had they been well-informed, non-coerced or/and repatriation facilitators fulfilled their duties. For example, researchers may have interviewed refugees after returned, and learned that they returned for reasons unrelated to coercion or misinformation.

Hypothetical Consent Scenario 2: Researchers know from other evidence that an individual would have had reason to repatriate had they been well-informed, non-coerced or/and repatriation facilitators fulfilled their duties to help them in other ways.

Hypothetical Consent Scenario 3: Researchers do not know, from other evidence, if an individual would or would not have had reason to repatriate were they informed, non-coerced or/and repatriation facilitators fulfilled their duties to help them in other ways.



In Scenario 1, because individuals would have no reason to return had they been informed and non-coerced, we also suspect that returnees would want us to look at their data. Importantly, we are still unsure if there was actually a lack of informed consent in the repatriation; we only know that the refugees say they had no reasons to return other than coercion or misinformation. As such, so there is a good justification for looking at the data, to find out if they were coerced or misinformed. However, these scenarios are rare. If we know an individual wouldn't have decisive reasons to return if she had been better informed, non-coerced, and/or provided other assistance, we probably also know if she was, in fact, misinformed, coerced and/or not provided other assistance. This would make looking at the data pointless in many cases. More worryingly, as before, if we look at their personal data and find out that returnees did, in fact, return without coercion or misinformation, then it seems they have not faced a major injustice, and would not have had a good reason to consent to disclosing their data after all. Furthermore, even if an individual was coerced and misinformed in repatriation, and only returned for these reasons, they may have other reasons to prefer privacy over disclosure. As before, they may fear information will leak, or their data may be of a private nature they do not want to reveal, such as their sexual orientation.

In scenario 2 individuals would have likely consented to return had they been better informed and less coerced. Looking at their data may still be ethical, because they may still feel wronged from the misinformation misinformed or coercion. Furthermore, though many claim they preferred to

return regardless of coercion or misinformation, they perhaps developed this preference because they are now forced to stay in South Sudan regardless. Returnees like Yasmin, who claim would have returned even if they had been better informed, may still want to hold repatriation facilitators accountable for their failure to inform. But though this is true, these individuals seem to have a lesser reason to consent to disclosing data compared to those who would have had no reasons to return had they been informed and non-coerced.

In Scenario 3, we know nothing before looking at their personal files. We may look at the data and find out that they had very good reasons to return, regardless of coercion and misinformation. We would then realize we have unjustly violated their privacy. We only have the facts that justify data disclosure after disclosing the data, in which case we may find out we have no justification at all. The dilemma remains: if we do not look at the data, we may never know that repatriation was without informed consent. If we look at the data, we may undermine the principle of informed consent for data disclosure.

There is one possible solution. We can employ what I call a “double hypothetical.” Let us say we try to answer the question “Would this person hypothetically want X?” and know that they likely want X if they like Y. But we have no on whether they like Y, so we instead ask “Would they hypothetically like Y?” For example, let us say I go to the shop to buy soft drinks for me a friend, not knowing if my friend wants orange soda or coke. I instead ask, “Does my friend like oranges?” but do not know this either.

I then consider if, hypothetically, she might like oranges. I recall that my friend once ordered a citrus fruit salad at a restaurant, and hypothesize that she likes oranges because she once ate a citrus fruit salad, and so hypothesize she prefers orange soda because she hypothetically like oranges. This hypothetical prediction to determine another hypothetical preference is not particularly good inferential reasoning, but it may be necessary when there is little information to draw upon.

Rather than ask, “Did the refugee have actual reasons to consent to repatriate if they were not coerced, helped in other ways, and informed?” we can start off by asking “Would the refugee have hypothetically had reasons to repatriate if they were not coerced, helped in other ways, and informed?” If the answer is “Yes” then this is evidence that they would not hypothetically consent to data disclosure. For example, I knew before meeting Joseph they he had been planning for years to open his own Playstation business. I also knew it was illegal for him to do so in Israel, and that he had saved money for an investment. I could hypothesize, before speaking to him in South Sudan, that he would have had reasons to return to South Sudan irrespective of whether he was coerced into doing so. Similarly, I could hypothesize that others had no reason to return. Many had no family connections in South Sudan, no capital saved, no basic education to find a job, and were of a minority group persecuted by the government of Sudan or South Sudan. Based on this, we can hypothesize that they would have had no reasons to return had they been fully informed and not coerced to leave. Based on this, we can hypothesize that they would consent to data disclosure.

As such, we can distinguish between three relevant scenarios:

Double Hypothetical Scenario 1: Based on other evidence, we can hypothesize that an asylum seeker would not have consented to repatriate had they been well-informed, non-coerced or/and repatriation facilitators fulfilled their duties.

Double Hypothetical Scenario 2: Based on other evidence, we can hypothesize that an asylum seeker would have consented to repatriate had they been well-informed, non-coerced or/and repatriation facilitators fulfilled their duties.

Double Hypothetical Scenario 3: We cannot even hypothesize if they would have consented to repatriate had they been well-informed, non-coerced or/and repatriation facilitators fulfilled their duties.

In Scenario 1, because we can hypothesize that an asylum seeker would have no reasons to repatriate had they been informed or un-coerced (or assisted in other ways), we can hypothesize that she would have had good reasons to consent to data disclosure after repatriation. In Scenario 2, we hypothesize that an asylum seeker would have returned regardless, and so hypothesize that she would not have reasons to consent to data disclosure. In Scenario 3 we still have the same problem of not knowing anything until we look at the data, but there are far fewer cases like Double Hypothetical Scenario 3 compared to the earlier Hypothetical Consent Scenario 3. For, cases with almost no information about a returnee can still be included in Double Hypothetical Scenarios 1 and 2, so long as we have some small

amount of information to make an hypothesis.

There are still cases, however, like Double Hypothetical Scenario 3, where all the information available is in the personal files. More importantly, we are on normatively shaky ground, with so many hypotheticals. Hypothetical consent is already quite removed from actual consent; hypothesizing reasons based on another hypothesis of reasons seems quite distant indeed. It can lead to clearly inaccurate conclusions about people's preferences. Imagine I am trying to figure out what soda my friend wants. I remember that my friend likes getting her vitamin C and detests refined sugar, and so hypothesizing that she prefers oranges over other foods, and so hypothesizing that she would prefer orange soda over water. Clearly, there is no vitamin C in orange soda and plenty of refined sugar. The hypothetical reasoning based on another hypothesis fails to remotely capture what my friend wants.

If we care about subjective preferences, this may be all we have to work with. We want to avoid simply resorting to what refugees' said they wanted before they repatriated. They signed a data protection form, while possibly being told, "You will be fine in South Sudan." When they weren't, we will never know that they were told otherwise.

### **2.3 Time**

Perhaps the problem is that we are relying on an earlier decision for the present time. If earlier decisions are invalid when enough time has lapsed, we can look at the data, regardless of a refugee's earlier stated preferences.

To consider when such an action would be legitimate, we must consider when, in general, earlier consent is valid for the present time. In many instances, it clearly is. If you consent to sell your car, and ownership has been transferred, this consent is binding. Other times, earlier consent is invalid if you change your mind, as when a patient consents to surgery and then, a moment before the operation, tells the doctor, “Stop!” The difference may be that, in the first instance with the car, there is no risk to bodily harm; in the second instance with the surgery, there is, and so earlier consent can be reversed. Indeed, some harmful consent will lapse automatically after some time, regardless of whether the consenter has explicitly stated that she changed her mind. If a patient consents to surgery in a year from now, a doctor should re-confirm her consent a year from now. He should not take her earlier consent as valid for the current time. Similarly, if a person says, “Punch me in a year from now” the consent seems invalid a year from now, unless we can ask them in a year from now, “Do you still want to be punched?” If they cannot be asked again, it seems punching them is wrong, because there is much harm from punching, and little gain. This is not to claim that self-harming consent should be viewed as invalid when it is for the present time.<sup>11</sup> Rather, self-harming consent for the future should be invalid. So while a person saying “punch me now” has possibly given their consent now, a person saying “punch me later” has not given their consent for later.

When refugees earlier consented to keep their data private, they were

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<sup>11</sup>V Bergelson, Consent to harm. In: Miller F, Wertheimer A (eds) *The Ethics of Consent: theory and practice*. Oxford: Oxford University Press 2013

consenting to future harm. This is because, in keeping their data private, they were giving facilitators the opportunity to hide any misconduct and negligence, giving facilitators one less reason to inform refugees of the risks. Refugees would then return, who otherwise would not have, and find themselves displaced or without basic necessities. As such, refugees' earlier consent to keep data private was a form of consent to future harm. If we cannot consent to being punched in a year from now, perhaps refugees cannot consent to keeping their data private in a year from now, when doing so is harmful in a year from now. As such, once a year passes, looking at data is justified.

There is a problem with this claim. Even if refugees agreeing to keep data private was a form of self-harm for the future, it is not harmful now. The repatriation has happened, and their lives cannot be made better or revived by disclosing their data. In this way, it contrasts to a person agreeing to being punched in the future; the future punch will hurt, and not punching in the future will not. Data privacy may hurt in the future, but keeping it private will not, once it is too late. In general, it would be wrong to treat earlier consent as illegitimate because of its harmful consequences on the current time, in cases where there is simply nothing to prevent these harmful consequences from transpiring in the current time.

There is a second consideration, other than self-harm. We can consider what a person will "retroactively endorse."<sup>12</sup> This is necessary in cases where a person's earlier decision was not valid consent – or might not be – and their

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<sup>12</sup>Parfit, *On What Matters*, Oxford: Oxford University Press 2011

current decision is also without valid consent, either because their judgment is impaired or they cannot be reached. This, too, is unhelpful. We have no idea what a former refugee will retroactively endorse after we disclose the data, because it is unlikely researchers be able to reach them in the future.

We could solve this by applying the idea of hypothetical consent to the idea of retroactive endorsement. We can hypothesize what they would retroactively endorse, were we able to contact them. This, however, simply shifts the problems of hypothetical consent I earlier discussed onto the problem of retroactive endorsement. We cannot even make a preliminary prediction of what they will later want until we ask them, which is impossible, or until we look at their data, which would be unethical without first knowing what they will later want. We could sometimes make a vague hypothesis without either asking them or looking at their data, but often we cannot. Furthermore, it seems wrong to rely on so many hypotheticals. We could be terribly wrong about the subjective preferences of those who returned.

### **3 Non-Subjective Reasons**

Perhaps the problem is that we are focusing too much on the subjective preferences of those who returned. In 2.1 I will consider the claim that, if data is disclosed, facilitators will be more accountable, and so other future refugees will experience a more ethical return, even if past refugees' privacy will be undermined. I shall ultimately conclude that this does not give us a



decisive reason to disclose the data. In 2.2 I argue that we should instead consider whether those who already returned have “object-given reasons” to disclose their data. These are reasons an individual has for acting a certain way, even if they do not subjectively feel they have these reasons. However, some may claim that this ignores subject-given reasons, which are reasons a subject would actually give for their actions. In 2.3 I argue that such subject-given reasons are not accounted for, regardless, when we keep data private. As such, we should place greater weight on object-given reasons to disclose the data.

### **3.1 Future Returnees**

Lives may be lost if we do not look at the data. Though privacy is important, future refugees will repatriate through coercion and misinformation if facilitators are never held accountable for past misinformed or coerced returns. If benefits are substantial, even a non-consequentialist may prefer breaching privacy.

But breaching privacy may, in the long term, undermine informed consent for repatriation itself. If refugees cannot be certain their data will be secure, they may refuse to give real answers when asked, “Why are you returning?” This may impair facilitators ability to ensure refugees are returning as freely as possible, and as informed as possible. For example, if a refugee hides the fact that she is homeless, out of fear that this will later be released to researchers, a facilitator will do little to help end such homelessness. Simi-

larly, if a refugee refuses to say her sexual orientation, for fear her privacy will be breached, then the facilitator cannot respond with information about the risks for homosexuals in the country the refugee is returning to. If facilitators are today warning individuals about risks in light of information refugees give them, then violating privacy may undermine current practices for ensuring informed consent.

Even if disclosing data will not undermine informed consent for repatriation, it may put the lives of past refugees at risk. As noted above, data can be leaked, and the more who see the data, the greater the risks.<sup>13</sup> Even if such consequences will not come about, it still seems wrong to look at personal data without consent. This is because the principle of informed consent is intended to be agent-specific. The aggregate benefit for other future refugees should not simply be weighed against the possible harm towards past returnees whose privacy we are invading. A returnee may not want anyone to know their personal information, such as their sexual orientation, or perhaps extremely personal reasons for choosing to repatriate, such as marital problems. If some acts are wrong even if they help many other people, it seems important to consider reasons related to the returnees themselves, and not other refugees who have yet to return.

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<sup>13</sup>T Schonfeld, JS Brown, NJ Amoura, B Gordon, You don't know me, but...: Access to patient data and subject recruitment in human subject research. *American Journal of Bioethics* 11(11)(2011)31–38

### 3.2 Object-Given Reasons

“Object-given reasons” are derived from objective facts about the world, rather than reasons the subject would herself give. In Parfit’s example, a person comes upon a poisonous snake. The snake is more likely to bite her if she runs away, as it is hostile towards moving targets. She doesn’t know this. She starts to run. She has a subject-given reason to run, but also a very good countervailing reason not to: the snake will bite her. This countervailing reason is derived from the objective facts that running away from this type of snake leads them to bite us, and that the subject does not want to be bitten.<sup>14</sup> Though these reasons for standing still would not be given by the subject, they are also not subject-neutral. They can concern the interests of the subject alone, in this case her interests to not be bitten. In this sense, it is different than either asking the subject what she wants, and also different than asking what everyone else would want.

To consider if data should be disclosed, we can consider whether returnees have object-given reasons to disclose their data. Many did before returning. Had they agreed to keep their files open, their return would be less coercive and more informed, which many preferred. In other words, they had reasons to disclose their data derived from the fact that discloser encourages a more informed and less coerced return, and the fact that they preferred to have a more informed and less coercive return. However, as I already noted, these earlier reasons are not relevant after return, because it is too late; if their

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<sup>14</sup>Parfit *ibid*

return was uninformed and coerced, there is nothing to do now once they have returned.

Though refugees have no reasons derived from empirical facts about the world, they may still have object-given reason to disclose their data. Some object-given reasons are derived not from empirical facts about the world, but from moral facts or professional codes.

For example, let us say a firefighter can easily put out a fire that would otherwise kill someone, but does not want to, because she is in the middle of her lunch break. We may think, “She has a very good reason to put out that fire.” Though she herself would not give a reason, she has a reason derived from the codes of conduct of her profession, or because as humans we have a moral duty to sometimes save lives if we easily can.<sup>15</sup> Similar to other object-given reasons, these moral object-given reasons needn’t be subject-neutral. To determine if a person has a reason to help others, we consider how much their own welfare is at stake. We would not, for example, claim that a firefighter has the duty to sacrifice her own life to put out the fire to save two other lives in the building. It may even be morally impermissible to do so if she is holding a baby in her arms, and the baby would be killed. One important non-consequentialist consideration is the absolute risks to harm an individual would face, and possibly the risks to children in their care. In this sense, appealing to object-given reasons allows us to move beyond only agent-neutral consequences, without limiting ourselves to subjective preferences.

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<sup>15</sup>Parfit *ibid*

In the case of repatriation, those who returned may have object-given reasons to disclose data to help other refugees, but unless one is an agent-neutral consequentialist, the aggregate consequences for others are not the only facts to consider. If disclosing their data risks their lives or the lives of their children, these returnees do not have moral object-given reasons to disclose data, even if it helps others. If, on the other hands, returnees would not be at risk from disclosing the data, and the data will reveal if they gave valid consent to repatriating, then they have reasons to disclose the data.

If we were certain of the subjective preferences of returnees, then these would be decisive. At the very least, they would hold greater weight than the object-given reasons I describe. However, when we do not know these preferences, object-given reasons become relevant, and must hold significant weight.

### **3.3 Why this does not ignore subjective preferences**

Does this approach ignore subjective preferences? There is one sense in which it does not.

Whenever we appeal to notions of autonomy and consent in deciding how to treat another person, and do not know their personal preferences, we often appeal to general characteristics about the person. For example, if a patient is in a coma, and her dog contracts a terminal illness, and we are not certain if she would want to have her dog euthanised, we may consider if she generally supports euthanasia for terminally ill and suffering dogs. If we have no

such general characteristics, we may appeal to characteristics about people in general. We might, for example, consider if dog owners tend to support euthenizing terminally ill dogs who are suffering. This same reasoning is currently applied to data privacy rules. It is generally accepted today that, because humans generally care about privacy, then this is evidence that many would not want their data disclosed unless asked. As such, when refugees repatriate, their data is kept private.

However, humans in general care about other values, besides privacy. They care about altruism. If, in general, this is true, then this is evidence that many returnees would want to disclose their data. If we keep data locked in a file cabinet, never holding repatriation facilitators accountable, we may be failing to respect their subjective preferences. To assume those who returned do not care about this hardly ensures their preferences are fulfilled.

Of course, humans care about more than just privacy and altruism, and each human cares about something slightly unique to herself. Unfortunately, we do not know these unique characteristics. Focusing on object-given reasons does not ignore subjective preferences. It simply provides an alternative consideration when we do not know what these subjective preferences are.

## 4 Weighing Reasons Against Each Other

Though object-given reasons are important, and are decisive when we have no information about subjective preferences, sometimes we do have partial evidence about subjective preferences. When we do, we must determine how we weigh object-given reasons against possible subject-given ones.

We can divide the reasons discussed so far into four possible categories:

1. Object-given reasons to disclose data
2. Object-given reasons to not disclose data, such as the effect it will have on the safety of past returnees
3. Predictions of possible subject-given reasons to disclose data, such as altruism or other personal reasons
4. Predictions of possible subject-given reasons to not disclose data, such as privacy or other personal reasons

If we were certain about a person's subject-given reasons, they might be the only ones that matter.<sup>16</sup> In this case, though, we are uncertain what individuals want, and can only hypothesize. In contrast, we can be relatively certain about some moral object-given reasons without looking at personal data. Perhaps the existence of certain object-given reasons should tip the

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<sup>16</sup>I assume that data disclosure is like surgery or sex: one's will is decisive, and that is the end of it. See D Groll, Paternalism, respect, and the will author. *Ethics* 122(4)(2012):692–720[2028?]

balance against possible subject-given ones. Whether they do depends on five considerations.

#### **4.1 Weak Object-Given Reasons**

Imagine a person is returning from Israel to Canada. They are unlikely to have been misinformed, or misinformed enough for us to claim their consent was invalid for such a safe choice. In such cases, there are only weak object-given reasons to disclose the data, because disclosing data does not significantly help to ensure informed consent in future repatriation. The subject is also unlikely to have subject-given reasons relating to altruism. If we were able to ask the subject, they would unlikely think, “I am helping others if I disclose data”. For, the data is not particularly helpful for others. In these cases, the possible subject-given reasons related to privacy are decisive, and data should not be looked at.

Object-given reasons can also be weak if disclosing data leads to detrimental consequences for the returnee. This might be case, for example, if disclosing data increases the chances of it being leaked to government authorities in the country the refugee returned to. Just as a firefighter has no decisive object-given reasons to sacrifice her life, because this is too demanding, no refugee would have a decisive object-given reason sacrifice her life for others. They would also unlikely to have subject-given reasons to, given that their lives are at stake.

Unfortunately, there is a correlation between the risks of disclosing data,



and the benefits of disclosing this data for others. It is precisely those who would be at risk from data leaking who we most want to know about, to find out if they were informed about the risks of return.

For example, consider the case of Ahmad, a Darfur refugee suffering from a mental illness, who was completely dependent on the wider Sudanese community in Israel to eat, dress, and access shelter. After years of the community sacrificing sparse resources for his survival in Israel, they told him to go to a psychiatric institution. He went, but left two days later. Community members, including those who fed and sheltered him, organized a meeting to decide what to do. He was not in attendance.

“We think it is best for you to return to Sudan,” they told him the next day. He objected. After more pressure, he finally went with a friend to a special unit of the Israeli Ministry of Interior (MOI) and asked to repatriate. The MOI provided him with a ticket and the location of the airport in Israel. He failed to show up at the airport, and was again pressured by the community to ask the MOI for help. At the second interview, the MOI official asked him, impatiently, “Do you really want to repatriate?” He responded that he no longer wished to repatriate, as he was too afraid. The official then told Ahmad that he could receive 500 Euro if he returned within a month. He agreed to return, and boarded a flight for Sudan, via Addis, in the summer of 2013. After repatriation, he disappeared at the airport in Khartoum, and no friends and colleagues in Israel or Sudan managed to locate him.<sup>17</sup>

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<sup>17</sup>I learned of this story from a member of the Sudanese community who had monitored the meetings leading up to his repatriation. Muhammad, personal interview, Tel Aviv, 8 August 2013

In Sudan, it is a criminal offense, punishable by death, to go to Israel. If so, it is surprising that the 500 Euro would be reason enough for him to repatriate. There is a strong likelihood that he was uninformed about the repercussions of repatriation, or lacked the mental capacity to comprehend the repercussions. Though disclosing data may place him at risk if the data leaked to Sudanese authorities, it is precisely because of these risks to his life that we may most wish to look at his data, to hold repatriation facilitators accountable.

We might think that Ahmad is unlike other cases. It was not that he lacked information or was forced to return, but that he lacked capacity. As such, rather than considering what he had object-given reasons to want, we should consider what was in his interests. This is the approach we take with incompetent patients;<sup>18</sup> if a patient is in a coma, or has severe mental impairments, then a surrogate will often consider whether releasing their data will harm the patient, with harm defined in terms of their health and psychological well-being. The same approach might be taken with refugees who returned. Refugees like Ahmad must have their interests considered, rather than what they had object-given reasons to do. However, even if Ahmad did not have full capacity, we must look at his psychiatric reports to validate this. To decide whether to look at these reports, we must consider if he had an object-given reason to disclose these reports. Ultimately, it seems he may have had no such reason if doing so risked his life. The object-given reasons here are therefore weak. The subject-given reasons are possibly also

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<sup>18</sup>N Cantor, The bane of surrogate decision-making: defining the best interests of never-competent persons. *Journal of Legal Medicine* 26(2)(2005):155–205

weak, as he would unlikely have a preference to disclose his data if this risks his life.

Perhaps researchers can take precautions to keep his data secure or only request data that would not disclose his identity. Nonetheless, NGOs and government agencies would possibly be justified in not disclosing his case file, if the consequences of it leaking are great enough. Unfortunately, if these NGOs and government agencies do not disclose this data, researchers would have no way of holding them accountable. There is clearly an unfortunate correlation between the type of data disclosure that would hold repatriation facilitators accountable, and the type of data disclosure that would risk the lives of returnees. We could make the same claim about our firefighter. It is often the case that a firefighter sacrificing her life would save more people than not sacrificing her life. There is a correlation between the sacrifice for her and the benefits for others. She still does not have a moral obligation to sacrifice her life. Similarly, the risks of harm from disclosing data seem to weaken the object-given reason to disclose the data, and also weaken evidence of subject-given reasons to disclose the data.

## **4.2 Strong Evidence of Subject-Given Reasons**

When we have strong evidence of subject-given reasons against data disclosure, we must consider if the evidence outweighs the importance of certain object-given reasons to disclose the data.

For example, some NGOs specialize in returning victims of human traf-

ficking. Many victims of trafficking do not want their personal data disclosed because the details are especially private. A similar claim may be made with regards to those who suffer from mental illnesses, information that may be especially sensitive for those who returned. If researchers know that those who returned fall into one or both these categories, this could be evidence of subject-given reasons to not want their data disclosed.

A returnee may also have already refused to give personal information, and so would unlikely to consent to disclosing their personal files. For example, if a refugee has already been approached by a researcher, and the refugee stated that they do not wish to provide any personal information, then this evidence of their preferences would outweigh the object-given reasons to disclose the data. It would almost be a case of an autonomous choice, and outside the scope of the very hard cases I address, where we know almost nothing about subjective preferences of those who returned.

Other times, a returnee has talked to a researcher in the past, describing a course of events that can be confirmed by looking at their personal files. Because the subject has already provided the data verbally in an interview, she would likely have subject-given reasons to disclose her data. Consider Adut, who I interviewed in 2012. While speaking into a recorder, she told me she had never lived in South Sudan, her parents having fled to Egypt before she was born. She married in Egypt, where she had three children, but was abused by her husband throughout their marriage. In 2010, while in Israel, she tried to murder her infant son. She went on trial, and the judge placed her in a hospital and her infant son in an orphanage. Shortly after, her husband

returned to South Sudan with their three eldest children, and Adut asked OBI for help returning, because she wanted divorce her husband and gain custody of her three eldest children. Her psychiatrist initially stated that she lacked the capacity to decide to return. OBI talked to the psychiatrist, Adut tells me. After that, he changed his mind.<sup>19</sup>

I tried contacting Adut several times throughout 2013. Someone else would always answer her phone, and state that she did not know where Adut was. I spoke with a UN official in Israel who was familiar with her case, and a documentary filmmaker who was making a film about her life. Both could not contact her. Nor could her mother in Australia, who had eventually adopted her infant son. I also failed to find her when I was in South Sudan in 2013 and 2014. Because of this, she could not give explicit consent for me to see the court document, her psychiatric medical history, and the questionnaire she filled out before return. As with Ahmad, even if she was misinformed about return or lacked capacity, we only know this for certain by looking at her reports. Unlike with Ahmad, the fact that she disclosed this data in an interview is evidence that she had subject-given reasons to disclose this information. This fact, combined with the object-given reasons, is enough to justify disclosing her data.

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<sup>19</sup>Mollie Gerver (2015), Repatriation and voluntariness, *International Journal of Human Rights*

### 4.3 Strong Object-Given Reasons

Sometimes object-given reasons are especially strong. This would be the case if we suspect, from other evidence, that facilitators misinformed refugees or coerced them to leave, but looking at the data is necessary to confirm our suspicions.

For example, government agencies and NGOs facilitating repatriation may clearly lack information on countries they are helping refugees return to. This would be strong evidence that there was a lack of informed consent, but not certain. When I spoke to the HIAS director in Israel, he emphasized how much more South Sudanese asylum seekers knew about South Sudan compared to HIAS, and how important it was to listen to the information refugees gave HIAS.<sup>20</sup> This was despite the fact that nearly all the returnees I interviewed in South Sudan had been born outside of, or had grown up outside of, South Sudan. Some had been born in Egypt, had not been in touch with anyone in South Sudan before return, and had never been to sub-Saharan Africa. If NGOs facilitating repatriation do not know about the country of origin, and those returning probably don't either, this is partial evidence there was no informed consent, but not complete evidence. A government dataset also revealed that most returning had either never lived in South Sudan or had left as small children. This is partial evidence that there was no informed consent, but not complete evidence. It seems especially important to look at data, assuming no refugees will be at risk from

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<sup>20</sup>HIAS, Personal Interview, Jerusalem, 11 December 2012

data leaking. This moral object-given reason to look at the data should have greater weight, even when there is only weak evidence of subject-given reasons to look at the data.

For example, Stephen, Yasmin and Joseph all said, in interviews, that they were never warned of the risks. To confirm if this is true, we need to look at their data. We should do this even though all three also said they did not feel wronged by the NGOs, and would unlikely have felt a subjective need to disclose their data to hold the NGOs accountable. When we already strongly suspect that NGOs did not provide accurate information, it is more important to establish this than to respect the possible preferences of those who returned.

#### **4.4 Partial Data to Avoid Dilemma**

There are cases where the object-given reasons are very strong, but so is the evidence of possible subject-given reasons. I met one woman in Aweil in South Sudan who did not want to be interviewed. We might feel she really would not have consented to data disclosure, but disclosing her data seemed especially important, as she was living in extreme poverty after return. Ahmad's case may be similar. He had strong object-given reasons to disclose the data, but they do not seem decisive, because of risks.

When we are still uncertain as to which reasons are decisive, we could compromise by only disclosing relevant data, and redacting the rest. Yet, in many cases, finding out if a professional body is blameworthy requires

looking at all data on the aggregate level. This is partly to ensure we don't wrongly blame repatriation facilitators. Facilitators cannot be expected to prevent all repatriation that is without informed consent. If we look at some cases, and learn that refugees were poorly informed, we cannot be certain if these cases are representative. For this we must look at all data, or a random sample.

For example, HIAS provided me partial answers from the case files of approximately 60 returnees. The files made clear that some returnees did not understand what they were returning to, and were largely repatriating because they had no refugee status in Israel. While this was of benefit for research, the benefit was severely limited. Such partial data could possibly violate both subject-given reasons relating to privacy without the benefit of the object-given reasons. For, we are looking at data without consent and also without much benefit for future returnees, because we do not know how pervasive coercion and misinformation is. Those who returned may also have been less likely to subjectively support such data disclosure if it does not help protect future returnees. Full data may uphold autonomy and object-given reasons more than partial data.

## **4.5 Enabling**

There is a final consideration we might appeal to when no reason seems decisive, but some choice must be made.

When we consider what principles to protect, we often consider whether,



in protecting the principle, we are undermining it. For example, if a person marches down the street, stating she will harm anyone who speaks out against the status quo, her freedom of speech should not be protected. For, in protecting her freedom of speech, we are undermining the freedom of speech of others, who now will be too afraid to speak out. When a principle is used to undermine itself, it seems less legitimate use the principle in this manner.

When NGOs, the UN, and governments follow the principle of informed consent with data privacy, this enables them to facilitate coerced and misinformed repatriation. This is not simply a conflict between rights. Rather, protecting informed consent at one point is used to undermine it at another, and so the principle of informed consent should be temporarily put aside.

We might still be concerned that disclosing data is using refugees who have returned, violating their right to privacy for the sake of future refugees' right to informed consent in repatriation. Furthermore, we do not know that NGOs and governments are using a principle to undermine itself. Rather, we just suspect this might be the case.

Though our concern for privacy should remain, it should not take priority because of an important asymmetry. If data is kept in a filing cabinet, we may be undermining informed consent for repatriation, because facilitators will not be held accountable, and we may also be undermining informed consent for data disclosure, because some returnees will not be able to disclose data they would have wanted disclosed, for altruistic reasons. In contrast, if we look at the data, we can at least ensure more informed consent for

repatriation for the future, even though we may be undermining informed consent for those who want to keep their data private. In other words, data privacy can enable uninformed or coerced returns, but uninformed and coerced returns cannot enable the violation of data privacy. As such, there is more at stake from keeping data private compared to what is at stake from disclosing data.

If we knew what returnees wanted, or the object-given reasons were weak, this would be irrelevant; the choice of the returnee would be decisive, or the disclosure unjustified. Given that we do not know what returnees want, and when no reason seems decisive, we look at the data.

## 5 Conclusion

Intervening in someone's life without their consent can result in the person being unreachable. When people are unreachable, they cannot consent to us looking at their data, including data that can determine if the intervention was without informed consent.

It is tempting to simply appeal to the consequences of invading privacy. Invading privacy can protect informed consent for others in the future and so it is justified. Such simple consequentialist reasoning, however, is not necessary. We can ask whether individuals have moral object-given reasons to disclose their data. This can account for consequences, but also the limits of what people should be morally expected to sacrifice. All of this, in turn,

can still be weighed against possible subject-given reasons. And when no reason seems decisive, we should disclose data, preventing coercive and uninformed interventions, even while undermining privacy. Such an approach can help ensure that the principle of informed consent is upheld, and does not undermine itself.